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ABSTRACT

This set of policy statements of the Illinois Planning Council on Developmental Disabilities, adopted from 1989 through 1990, documents Council philosophies and beliefs about issues impacting persons with developmental disabilities and their families. The value standard guiding all Council policies, plans, practices, grants, and advocacy is consideration of the question: "Would I willingly accept this for myself or any of my family members who are disabled?" Specific statements address the following areas: the offender who is developmentally disabled; transition from school to adult life; the role of education in preparing students with developmental disabilities for adulthood; employment; least restrictive environment; care and treatment of infants with developmental disabilities; child care; transportation; persons with developmental disabilities and the use of psychotropic drugs; employment and income support; family support; Acquired Immune Deficiency Syndrome (AIDS); case management; community living; early intervention; free and appropriate public education; prevention; and use of severe punishment or aversives with persons with developmental disabilities. (DB)

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Policy Statements of the Illinois Planning Council on Developmental Disabilities

June, 1991

EC 301034

Policy Statements
of the
Illinois
Planning Council
on
Developmental
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INTRODUCTION

The beliefs and values that society has held about people with developmental disabilities has changed dramatically over the past years. It is important that an advocacy agency, like the Illinois Planning Council on Developmental Disabilities, agree on what their philosophies, beliefs, and values are. These common values and beliefs can then direct our decisions and actions.

The Illinois Planning Council on Developmental Disabilities has adopted Policy Statements to document Council philosophies and beliefs about issues impacting persons with developmental disabilities and their families. These Policy Statements are documents that may be revised as "best practices" in the field of developmental disabilities change. It is the intention of the Council that our future directions and actions be grounded in the beliefs and philosophies presented in these Policy Statements.

The Council Value Statement contains a passage quoted below that serves as the foundation for our Policy Statements.

" . . . Recognizing that people with disabilities have the same wants, desires, aspirations, dreams, feelings, and rights as do people without disabilities, the Council policy is that persons with disabilities shall have the same opportunities throughout their lives for happiness and personal achievement as do people without disabilities . . .

The standard against all Council policies, plans, practices, grants and advocacy shall be embodied in the following question, 'Would I willingly accept this for myself or any of my family members who are not disabled?' "



IPCDD VALUE STATEMENT

Adopted on March 14, 1989

Introduction: Recognizing that persons with disabilities have the same wants, desires, aspirations, dreams, feelings, and rights as do persons without disabilities, the Council policy is that persons with disabilities shall have the same opportunities throughout their lives for happiness and personal achievement as do persons without disabilities. Funds and services must follow people with disabilities to enable and empower them to achieve these goals.

The standard against which all Council policies, plans, practices, grants and advocacy shall be evaluated is embodied in the following question, "Would I willingly accept this for myself or any of my family members who are not disabled?"

As developmental disabilities have many causes and origins, efforts toward prevention must cover a broad range of social, environmental, media and health-related activities.

Persons with Developmental Disabilities and their Families: Persons with developmental disabilities and their families shall be educated and empowered to enable and support, through each family member's participation in the family unit, the personal achievement and happiness for each member of the family and the family unit as a whole.

Community: Citizens with disabilities, of all ages, shall have the same opportunities and responsibilities to participate in their local community as do citizens without disabilities.

Home: At all ages, persons with disabilities shall have the opportunity to live in homes similar or identical to the homes of persons without disabilities in the same community.

School: Students with disabilities shall have the opportunity to attend the same school as the other students of the same age and neighborhood. As with other students, the purpose of school for students with disabilities is to prepare them for life after school and to increase their opportunities.

Work: with disabilities shall have the same access and career opportunities within and throughout their community as do people without disabilities.

Play and Leisure: Through life, people with disabilities shall have the same opportunities for play, leisure and recreation as others in their communities who are not disabled.

THE OFFENDER WHO IS DEVELOPMENTALLY DISABLED POLICY

Adopted on March 8, 1990

Like all citizens, individuals with developmental disabilities are accountable and responsible for their actions. All persons with developmental disabilities who break the law, like all other citizens, should be subject to arrest, prosecution and if convicted, appropriately sanctioned (or penalized for not complying with the law).

As part of this accountability, the justice system (police, prosecution, defense bar, the courts, probation and corrections) must make every effort to assure equal access to justice for individuals with developmental disabilities. Access is defined as not only physical access but on a more fundamental basis, access to equal and fair treatment under our system of justice. Such access ranges from special assistance to offenders with visual or hearing disabilities to special advocates for offenders with mental retardation who may not fully understand the workings of the justice system. Equal access must also be a guarantee that the justice system has a basic understanding of those issues related to developmental disabilities which might impact upon the adjudication process. Additionally, equal access to justice is assuring that the justice system, its component parts, and officials are aware of the disability of the individual and understands its implications.

Significant numbers of individuals with developmental disabilities pass through the justice system unidentified. The consequence of this ignorance is unknown but surely works to the disadvantage of the community, the individual and our commitment to justice. At the very least, the failure to identify the individuals with developmental disabilities during the adjudication process denies the individual and the justice system access to services which may contribute significantly to the cessation of further criminal behavior. The Illinois Planning Council on Developmental Disabilities shall work with the justice system to promote equal access to justice through education and promote coordination between the justice system and the service delivery system for developmental disabilities.

In setting forth the assertion that individuals with developmental disabilities are accountable for offenses which they commit, the Illinois Planning Council on Developmental Disabilities also strongly advocates for the courts to consider the disability in setting appropriate sentences for those individuals convicted. The only exceptions are those individuals who, due to their disability, are found unfit to stand trial. No individual with mental disabilities should be sentenced to death.

The Illinois Planning Council on Developmental Disabilities also supports the equal availability of the least restrictive sentencing option consistent with public safety, combined with a coordinated habilitative program. The Illinois Planning Council on Developmental Disabilities recognizes that there are offenders with a developmental disability who should be incarcerated for the safety of the community and themselves. The vast majority of offenders with disabilities, however, can be better served through a coordinated community-based supervision/services approach. The development of programs should be promoted which provide more appropriate sentencing options for the courts when dealing with offenders with disabilities. An increase in the capacity of existing sanctions (or penalties) should be promoted to appropriately respond to the offender with developmental disabilities.

TRANSITION FROM SCHOOL TO ADULT LIFE POLICY

Adopted on March 8, 1990

Transition is a concept that has been used to describe times of change in a person's life. Although everyone experiences many transitional periods throughout their lives and every transition has unique concerns, a person's immediate adjustment beyond high school has been identified as a top priority by consumers, educators, and human service agencies. During the school-age years, the rights of persons with developmental disabilities to education in the least restrictive environment have been established through Federal law. Unfortunately, the equity of lifestyle attained by school-age persons with disabilities and those without disabilities begins to diverge upon school exit. Follow-up studies of students with developmental disabilities who leave school have consistently revealed high levels of unemployment, underemployment, dependence, isolation, and segregation from integrated community activities.

Transition from school to adult life has emerged as a focal point for centering attention on the diversity of lifestyle issues that must be addressed in fulfilling the promise and intention of mandatory public education. Accordingly, transition should be viewed as a dynamic process involving a partnership of consumer, school-age services, and post-school services that result in people attaining maximum levels of employment, independent living*, integration, community participation, and productivity. A comprehensive transition process should include individualized planning, community organization and support, and statewide interagency coordination.

Formal transition planning for all persons with developmental disabilities should begin no later than the age of 14 as part of the Individual Education Plan, and involve collaborative planning regarding a person's goals upon leaving school and needed support services. At a minimum, this planning and realization should include people's desires and choices for employment, continuing education, leisure-time use, and immediate and long-term housing. In order to more fully understand the realm of their choices, students and their parents must be given up-to-date information and must be given the opportunity to visit a multitude of places where the student with disabilities may be able to live, work, and recreate after graduation. Consumers, school personnel, and selected human service agency representatives should use transition planning and realization to define and refine a student's goals upon leaving school and needed services to accomplish the desired lifestyle. The transition planning process provides the opportunity to focus attention on the unique problems that must be solved to enable individuals to move directly from schooling to an adult lifestyle of independence, productivity, participation, and integration in the community.

* "Independent Living" refers to the ability of persons with disabilities to exercise personal control over their own lives, to have freedom of choice and to participate actively in society – including home, family, social activities, and work

Transition planning is most importantly an outcome-oriented process. The purpose of the process is to enhance the quality of life experienced by persons with disabilities as they move from schooling to an adult lifestyle in the community. Transition planning needs to reflect a comprehensive concern for: 1) the individuals with developmental disabilities; 2) opportunities and resources in the local community; and 3) the coordination of interagency policy. Quality of life outcomes such as employment, independent living, community integration, participation, and productivity should be used to evaluate the effectiveness of individualized transition planning, community organization and interagency coordination.



THE ROLE OF EDUCATION IN PREPARING STUDENTS WITH DEVELOPMENTAL DISABILITIES FOR ADULTHOOD POLICY

Adopted on March 14, 1989

The role of education in the lives of people with developmental disabilities is critical. for this system serves students during their important developmental years when the course of their future is charted. The outcomes of independence, integration and productivity should guide the educational system in serving children and youth with developmental disabilities. To achieve these outcomes, it is essential that the educational system stresses teaching skills that will be useful to the individual student now and in the future, in integrated, age-appropriate school and community environments. In addition to the core curriculum, programs for students with developmental disabilities should incorporate instruction in social skills, problem-solving, decision-making and self-advocacy, and should include structured planning for transition to adult life.

INDEPENDENCE: Curricula and teaching methods should focus on enabling students with developmental disabilities to become increasingly independent. Curriculum and instruction should stress useful age-appropriate skills, enhance independence and help students gain a measure of control over meeting their own basic needs. For some students, independence will mean performing self-care, daily living and/or academic tasks without assistance. For others, it will mean increasing the degree to which they are able to meet their own needs and decreasing, in some degree, their reliance on support from others. For all students learning independence requires making increasingly independent decisions, solving problems, and exercising choices. A sense of independence will contribute to students' healthy self-image and belief in their abilities.

Enabling students to increase their independence requires having high expectations for their ability to learn and for their eventual participation in adult society. The meaningful participation of adults with disabilities as role models is critical to this process. Because of each student's unique needs, the educational program should be individually tailored and should employ assistive devices, augmentative communication systems, non-aversive behavior management, and current technology as needed, beginning in the pre-school years. In addition, individualized educational programs must incorporate, in all dimensions of instruction, specific provision for teaching decision-making, problem-solving and self-advocacy skills and provide structured opportunities to exercise those skills in natural environments. It is especially critical for students with severe cognitive disabilities that development of problem-solving and decision-making skills be consciously and deliberately incorporated into every aspect of the educational plan. This requires providing opportunities to recognize that choice is available, to exercise choice, and to experience the consequences of one's own choices.

INTEGRATION: Integration encourages acceptance of diversity, and respect for individual differences and abilities, while fostering the development of friendships and other significant relationships. Students with disabilities have the right and should have the opportunities to be educated in the same educational environment as any other student. The type of environment in which students grow will have a powerful impact on their development. Educational environments in which children with developmental disabilities are integrated with students their own age who do not have disabilities will be better able to prepare them for adult life in the real world. All school facilities and programs should be completely accessible. Any services or supports needed to accommodate a student's disabilities should be brought into the general education environment, and should be individually designed and implemented for each student. Specialized services, such as speech, physical and occupational therapy, and non-aversive behavior management must be provided for each student, as needed, within the regular school environment. Such integration of students requires joining together various administrative functions of general, special and vocational education.

Integration is not something that "just happens" through physical relocation. Merely mixing students with severe disabilities with their peers who do not have disabilities may not result in changes that allow frequent and natural interactions. Planned and structured preparation may be needed for participants when integration is introduced in a school, if it is to benefit both students who have disabilities and their peers who do not have disabilities. It is necessary to include students and parents, as well as regular education teachers and administrators in planning for integration; to provide them with information about disabling characteristics and the needs of people with disabilities; to organize sensitivity sessions and structured interactions with special education students; and to facilitate communication through training in sign language, provision of interpreter services, and/or other means.

Integration does **not** mean locating special education classes in separate wings, grouping students with a wide range of disabilities and needs, providing separate transportation, placing older students with disabilities at schools for younger children, maintaining separate schedules for students in special education and regular education, or placing older students with disabilities in segregated adult facilities. All possible opportunities for students with disabilities to join in the social and extra-curricular experiences of school life must be provided to students with developmental disabilities, to enhance the important interpersonal skills that will be needed throughout their lives.

PRODUCTIVITY: The school's role in promoting productivity for its students with developmental disabilities should begin as early as possible, with activities designed to teach students communication and social skills; to familiarize them with basic work concepts, various jobs and careers; and to have opportunities to contribute to others.

It should continue at the middle school or junior high level with emphasis on interpersonal skills, independent functioning skills, attitudes, and appropriate work related behaviors. For high school students, vocational and community living skills should be taught in the community as well as in school. A variety of job placement experiences, whether during school hours or after school, should be available to secondary students with developmental disabilities. Their individual interest and work abilities should be carefully explored to assure they are moving toward meaningful work.

TRANSITION: At least five years prior to graduation, the educational system should initiate formalized transition planning, and should link the young adults with developmental disabilities to appropriate adult services and supports, to assure a smooth transition to job placement or advanced educational or training opportunities, and living in the community.



EMPLOYMENT POLICY

Adopted on March 14, 1989

A basic value of American society is that citizens are productively employed and receive a reasonable wage for their work. For people with disabilities, this is best achieved through the preferred option of integrated work. It is the policy of IPCCD that people with developmental disabilities who want jobs should have the opportunity to be productively employed without jeopardizing other rights or benefits which assure them necessary continuing support.

In recent years, more and more people with developmental disabilities are working. Increased productivity of people with developmental disabilities, encouraged by improvements in the human services disability network and more humane attitudes toward people with disabilities, is helping to change the environment of the larger society. The design and management of services must reflect these changes in a way that retains focus on meeting people's needs while enabling independence, productivity and integration.

Further, it is the responsibility of society to act affirmatively in making employment opportunities and necessary support services available to persons with developmental disabilities.

When providing employment opportunities, certain principles should be observed and implemented. They are:

- (1) **INDIVIDUAL CHOICES:** Individuals are to be involved in all aspects of decision-making that affects their lives. Choice and decision-making should be well informed, and must include direct experience in the options from which the individual will make a choice or decision. The preferences of people with developmental disabilities must be honored. Their integrity, dignity, growth, and contributions must be encouraged. Career planning, counseling, and work experience for people with developmental disabilities should start in early elementary school years as they should for people without disabilities. Career planning assistance should be made available as desired over the person's lifetime and should include retirement planning.
- (2) **A NATURAL ENVIRONMENT:** Employment should occur in environments which offer the opportunity for integration with peers without disabilities. Employment should be in typical work settings rather than in segregated, sheltered programs. The proportion of employees with disabilities to employees without disabilities in the workplace should not be greater than that occurring in the general population. Workers should be paid in accordance with the Fair Labor Standards Act and with priority for prevailing or minimum wage. Benefits available to workers without disabilities should be available to workers with disabilities.

- (3) **SUPPORT SERVICES:** All supports should be determined and provided on the basis of the individual's needs, preferences, and in keeping with the individual's chronological age group. The degree and kind of support should be flexible and should be time limited, extended or ongoing, according to individual need. Supports may be provided at work, and to transport an individual to and from work. The goal of all supports is to enable the individual to engage productively in meaningful work.
- (4) **EMPLOYMENT STRATEGIES:** Job opportunities should be available with options for both upward and lateral mobility. There should be an array of employment options including: competitive employment, small business and self-employment opportunities.
- (5) **RELATIONSHIP WITH BUSINESS AND LABOR:** The participation of business and employers is essential. Individuals assisting people with disabilities should at all times work with business and labor in developing ways to meet work force needs, in job development and creation, and dealing with workplace issues. The participation of organized labor should be recognized with regard to issues which affect workers with disabilities and without disabilities. Every effort should be made to demonstrate the economic importance and viability of supported employment so that its job creation and development possibilities will be understood by the business and economic development leaders of the state and community.
- (6) **INTERAGENCY COLLABORATION:** At the local and state level, cooperative working agreements, clearly specifying areas of responsibility, should be developed among those who provide employment services and supports. Local entrepreneurial agencies should be encouraged to provide a wider range of opportunities and choices for people. At the state level, interagency agreements should also address, but not be limited to intergovernmental and state-federal relationships, with particular attention to SSI/DI, transition from school to adult life, transportation, Medicaid, and Department of Labor policies.
- (7) **EDUCATION AND CAREER DEVELOPMENT:** People with disabilities have the right and should be afforded the opportunity for career development and lifelong education. This should include all educational opportunities afforded by institutions of higher education and should provide choices and opportunities for growth over the lifetime.



LEAST RESTRICTIVE ENVIRONMENT POLICY

Adopted on March 14, 1989

It is the policy of the Illinois Planning Council on Developmental Disabilities that services for people with developmental disabilities take place in the "least restrictive environment." The least restrictive environment means that services do not restrict an individual's choice and allow options in settings with peers who do not have developmental disabilities.

IPCDD believes that educational, residential, employment, transportation, social and recreational supports in the least restrictive environment will enhance the personal development and minimize interference with individual freedom for people with developmental disabilities. Services in the least restrictive environment will enhance maximum personal independence, integration into the community and productivity of the individual. It will also provide a common meeting ground where persons with and without developmental disabilities can learn from and grow with each other.

IPCDD further believes that decisions relating to least restrictive environment should be made by a team composed of the person with whom the decision is being made, parents or guardians when appropriate, advocates, and professionals. Decisions should be based on future as well as present benefits for an individual. For this reason, environmental settings and circumstances should be evaluated at least annually to ensure continuing appropriateness and effectiveness. In the event of abuse, neglect, unsafe conditions, or homelessness, a person with developmental disabilities may need short term protective services.

In order to assure that services are provided in the least restrictive environment, it is imperative that each service for each individual be monitored for outcomes. The monitoring team should include the person with the developmental disability, parents or guardians when appropriate, advocates, and professionals. Following monitoring, necessary corrective actions should be planned and implemented immediately.

CARE AND TREATMENT OF INFANTS WITH DISABILITIES POLICY

Adopted on September 21, 1989

The Illinois Planning Council on Developmental Disabilities (IPCDD) opposes the withholding of medical treatment and/or sustenance to infants when the decision is based upon the diagnosis of, or prognosis for, retardation or any other disability. IPCDD affirms the right to equal medical treatment for all infants in accordance with the dignity and worth of these individuals, as protected by federal and state laws and regulations. IPCDD acknowledges the responsibilities of society and government to share with parents and other family members the support necessary for infants with disabilities. Finally, IPCDD acknowledges the obligation of society to assist with lifelong medical, financial and educational supports to persons with disabilities extending to them opportunities offered to all members of society.

CHILD CARE POLICY

Adopted on September 21, 1989

Quality child care is a necessity, not a luxury. The Illinois Planning Council on Developmental Disabilities (IPCDD) recognizes that parents want to be involved in decisions affecting their children. The IPCDD further recognizes that parents and children are not homogeneous groups, that time is a precious commodity for both parents and children, and that parents of children with disabilities may have careers or other pursuits outside the family structure.

It is, therefore, the policy of the Illinois Planning Council on Developmental Disabilities to support:

1. equal access for children with disabilities to community programs including child care, day-care homes, pre-schools and latchkey programs designed for children without disabilities.
2. the right of children with disabilities to grow up in typical settings with their typical peers, and to attend local, neighborhood child care programs with other children who may or may not experience disabilities.
3. choices for children with disabilities and their families based on family values and lifestyles, heritage, and individual needs.
4. fiscal policies and regulations for child care programs which make child care available, affordable and accessible to children with disabilities, and
5. training of child care staff, necessary supports and aids allowing children with disabilities to participate.

IPCDD is committed to working with other agencies to achieve national, state, and local support for a quality child care system for all children which includes:

1. consistent, loving caregivers who are trained and are fairly compensated for their work.
2. safe, warm, cheerful accessible physical environments with adequate space.
3. developmentally and culturally appropriate books, materials, equipment, and programs.
4. small group size and low child/helper ratios.
5. adequate and nutritious food.
6. an information resource and referral system for parents and providers.
7. active parental involvement, education, and support.
8. activities which support children's needs to achieve independence, and
9. community support from public and private sector organizations and individuals.

TRANSPORTATION POLICY

Adopted on September 21, 1989

Within our society, the freedom of movement is an essential component of any effort to enable all citizens to live as independently as they choose; to engage in productive self-sustaining activity; and, most importantly, to be fully integrated within their communities. A transportation system must meet the needs of citizens in an accessible and affordable fashion.

It is, therefore, the policy of the Illinois Planning Council on Developmental Disabilities (IPCDD) that all people with disabilities should have access to all publicly funded and/or regulated transportation services. It is further the policy of IPCDD that:

- (1) All publicly funded transportation services developed in the future must be architecturally, physically (mechanically) and programmatically accessible to people with disabilities.
- (2) Any and all expansion, renovation or equipment replacement in existing publicly funded or regulated transportation services must be done in such a way as to remove all existing architectural, physical or programmatic barriers.
- (3) Government at all levels must develop accessible and affordable transportation options including paratransit for people with disabilities and others dependent on public transportation.
- (4) Paratransit, for people with disabilities, must be understood as a necessary component of, but not as a substitute for, accessible public transportation.
- (5) The federal Urban Mass Transportation Administration must adopt and enforce user compliance standards as a condition for public transit systems obtaining and maintaining transit equipment purchased with federal funds.
- (6) Local transportation authorities, after consultation with knowledgeable consumer groups, must provide education to transit personnel to sensitize them to the transportation needs of people with disabilities, as well as "user-side training" for people with disabilities.

PERSONS WITH DEVELOPMENTAL DISABILITIES AND THE USE OF PSYCHOTROPIC DRUGS POLICY

Adopted on September 25, 1990

The Illinois Planning Council on Developmental Disabilities recognizes that behaviors exhibited by individuals with developmental disabilities do not exist in a vacuum and may indicate physical illness, situational distress, or environmental conditions. The Illinois Planning Council on Developmental Disabilities believes psychotropic medication should never be used until a comprehensive individualized functional analysis of the behavior including the individual's communicative intent, and a complete medical evaluation have been conducted. Further, documented interventions based on a comprehensive assessment should be implemented and analyzed prior to any decisions to resort to the use of psychotropic medications.

Furthermore, the Illinois Planning Council on Developmental Disabilities opposes the use of psychotropic medications with individuals with developmental disabilities when used to suppress behavior and/or as a punishment.

When the utilization of psychotropic medication is indicated with persons with developmental disabilities, a systematic approach with optimal medication management is essential. The systematic approach to medication management must address major concerns regarding indications for the use of psychotropic medications, the determination of minimal effective doses, and the systematic monitoring for tardive dyskinesia and other side effects.

Use of Psychotropic Medication

It is the policy of the Illinois Planning Council on Developmental Disabilities that the individual's record should include:

- A description of the behavior to be modified (target behavior) and medically treated;
- Expected behavioral outcome or actual outcome;
- A systematic data collection procedure and appropriate data base with which to evaluate drug effectiveness;
- Possible secondary or side effects;
- Dates for review or termination;
- Review and discussion of alternatives available and why medication is preferred.

Furthermore, the Illinois Planning Council on Developmental Disabilities (IPCDD) supports the policy that psychotropic medication shall not be administered:

- For punishment;
- For suppressing behavior that is typically related to staff convenience (i.e. lack of adequate staffing, intervention, programming, etc.);
- In excess of minimal effective doses or duration of prescription;
- In quantities that may interfere with a person's positive growth and development; and
- As a substitute for a positive program.

Determination of Minimal Effective Doses

It is the policy of the Illinois Planning Council on Developmental Disabilities that the use of psychotropic drugs for persons with developmental disabilities can be significantly reduced by utilization of a structured review process emphasizing target behavior definition, data collection, and alternative non-drug treatment approaches.

Side Effects

It is the policy of the Illinois Planning Council on Developmental Disabilities that a process(es) be in effect to:

- Review, report and document psychotropic medication side effects; and
- Specify the method to achieve the detection of side effects for each individual.

EMPLOYMENT AND INCOME SUPPORT POLICY (SSI/DI)

Adopted on December 14, 1989

The realistic fear of loss of eligibility for Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) is a major barrier which prevents many individuals with developmental disabilities from becoming employed. The policy of the IPCDD is that people with developmental disabilities must have the opportunity to be productively employed and earn real wages without jeopardizing their eligibility for programs and services. Specifically, for those wage earners with developmental disabilities who require support services.

- the monetary value of such support services should not be counted as part of the individual's income when determining eligibility for services and benefits, and
- the maximum allowable income for service and benefit eligibility should be sufficiently high so as to reflect the increased cost of living borne by persons who require support services and/or adaptive equipment and supplies.



FAMILY SUPPORT POLICY

Adopted on December 14, 1989

The commitment of families is the greatest resource available to persons with developmental disabilities. This vital resource must be recognized and strengthened if the goal is to improve the lives of persons with developmental disabilities and to promote their independence, productivity, and full participation in all aspects of community life. The concept of Family Support involves supporting the commitment of families by enhancing family unity and enabling the family to access the resources that are necessary to assist the family in its caregiving role. Family support is intended to build on the family's strengths so that the family is able to derive maximum benefit from the resources available to it.

Over the life span, all families inevitably face a variety of stresses and challenges. The quantity and quality of resources that families have available to them affect the way in which the family is able to adapt to the stresses it experiences. These resources range from personal characteristics, such as coping strategies and problem-solving skills; to informal supports, such as friends, neighbors and extended family; to formal supports, such as services provided by public and private agencies. Each family is unique in its capacity to adapt to the stresses it faces, and this capacity may change across situations and over time. Families who have a member who has a developmental disability are often faced with extraordinary physical, economical and emotional challenges that may necessitate the provision of additional supports to enhance the resources already available to them.

Family support is the provision of necessary resources to families in order to strengthen the family unit and decrease family stress. Families with a member who is developmentally disabled and who lives at home experience a variety of challenges and exceptional caregiving demands that result in special needs in all areas of family life. Families of persons with developmental disabilities should receive the necessary supports to maintain their family member at home while enhancing the family's capacity for caregiving. Family support should be designed to promote the independence, integration, and productivity of the individual who is developmentally disabled, as well as to foster family unity and reduce family stress.

Family support must focus on the family unit. Family support should be broadly defined so as to respond to the needs of all members of the family, including the individual with a developmental disability, parents, siblings, and other extended family members living within the household. This approach recognizes that all members of the family constellation have an impact upon one another's lives, thus the unified well-being of the family will enhance the quality of life for all members, including the family member who is disabled.

All children, regardless of disability, belong with families and need enduring relationships with adults. The presence of a disability, no matter how severe, should not deny a child's basic right to a nurturing home and family life. Children with developmental disabilities should live with their natural families whenever possible, and necessary supports should be provided to enable families to care for their children at home. When children cannot remain with their natural families, for any number of reasons, they deserve the opportunity to live with other families, or in other family-like settings. In these instances, permanency planning, such as reunifying the family, pursuing adoption or foster care, etc., should be used as a guiding philosophy.

Family support is needed throughout the life span of the individual who is developmentally disabled. Family needs change over the course of the family life cycle, thus requiring that an array of services and options for services be available to families of persons with developmental disabilities. Support is particularly crucial during periods of lifecycle transition, such as when the family member with developmental disabilities is exiting the school system or is preparing to live more independently, outside the family home. Families need to be assured that systems/services will be in place to guarantee the well-being of their family member with a disability. Assistance with future planning should be included as an essential component of family support.

Strategies for supporting families of persons with developmental disabilities should be designed with sensitivity to the unique strengths and needs of families. Families should participate in the development of an array of support services from which to choose in order to meet their needs on a short-term, emergency, or long-term basis. Rather than forcing the family to "fit" the available service(s), family support should be flexible, individualized, and responsive to the needs identified by the family. Family support should be based on the assumption that, unless determined unfit, families are the experts who are best able to determine what services and supports they need.

Families should have convenient, quick, and easy access to services to meet their needs. Coordination of services which allows efficient linkage to appropriate resources should be available. In addition, a crucial element of family support is access to state-of-the-art information that can empower families to resolve many of their own needs related to caring for their family member with a developmental disability.

Families' needs should be met by utilizing natural supports within integrated community environments to the greatest extent possible. The use of natural supports in the community, including neighbors, extended family members, friends, religious organizations, schools, community associations, etc., should be encouraged as the primary resource for families. When families require specialized support, professional or agency-operated support services should be arranged. These services should maximize integration and participation of the entire family in the community by strengthening the already existing natural support network and helping to connect the family to community resources.

ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS) POLICY

Adopted on May 24, 1989

Acquired Immune Deficiency Syndrome (AIDS) is a serious health threat to all people of the world, including people with developmental disabilities. AIDS is fatal. During its progression, mental and physical disabilities develop in the person who has acquired the disease so that even people who did not previously have disabilities will often develop them.

Increasing numbers of infants are being born with AIDS and most infants who are born with AIDS will acquire a developmental disability. Children who lack access to adequate health care, live in urban poverty or have poor health, comprise the vast majority of pediatric AIDS cases. Children and adults can also be infected through blood transfusion, sexual contact, and high risk behaviors such as intravenous drug use.

AIDS is a preventable disease, and education and consequent behavior changes can protect an individual from contracting the disease. Although children and adults with developmental disabilities are no more susceptible to the disease than other people, education and training efforts must take into account the special learning needs of people with developmental disabilities. The societal discrimination that is so prevalent in the lives of people with disabilities is amplified when the individual has Human Immunodeficiency Virus (HIV) which encompasses all terms, including AIDS, AIDS related complex, or the AIDS virus.

The Illinois Planning Council on Developmental Disabilities (IPCDD) supports:

- (1) continued and immediately expanded research efforts for a cure for this disease and amelioration of its effects;
- (2) continued and immediately expanded home and non-hospital-based services to support the humanity and dignity of all people with the disease, including people with developmental disabilities who have the disease;
- (3) continued and immediately expanded efforts for prevention of the disease in infants and young children, including the provision of mandated AIDS education which is accessible to people of all ages and adapted to all abilities, including people with developmental disabilities;
- (4) continuously updated, mandatory public education must be made available to persons of all ages and abilities, including people with developmental disabilities, that will allow the choices and behavior changes necessary for the prevention of the disease in individual cases;

- (5) a functional approach should be used in describing the service needs of a person rather than the use of the diagnosis AIDS. Services should match needs. The array of services may include, but is not limited to: in-home services, housing, hospital, case management, social services, sex education, employment, residential services, physical therapy, equipment, social work, occupational therapy, early childhood intervention, public education and nursing. These services should be accessible, nondiscriminatory and consistent with the least restrictive environment principle;
- (6) every agency should have written policies and procedures regarding staff, volunteers and consumers who may contract HIV. These guidelines, policies and procedures should be prepared in consultation with interested groups such as individuals, families, health personnel, legal experts, staff, administrators and board members. These policies should cover admission procedures, treatment, confidentiality, due process, hygiene practices, in-service training, financial responsibility and continuing employment conditions;
- (7) blood testing or screening for HIV should follow the same guidelines as for the general population. Testing should not occur without informed consent, a clear medical indication to test, or a real and imminent danger to others and should be accompanied by education and support of qualified professionals. Consent procedures must be followed. Confidentiality must be maintained; and
- (8) coverage under Section 504 of the Rehabilitation Act must be extended to persons with HIV.

CASE MANAGEMENT POLICY

Adopted on May 24, 1989 — Revised on December 14, 1989

The term case management services means a lifelong goal-oriented process for the coordination of the range of services needed by persons with developmental disabilities and their families who require this service. Case management services are designed to ensure accessibility, continuity and accountability and to maximize the potential of persons with developmental disabilities for independence, productivity and integration into the community. Case management services should be available to all persons with developmental disabilities, regardless of age, type of disability, degree of impairment, place of residence or status as a recipient of services from any state or private agency. Case management services, at a minimum, include:

- (a) Outreach to identify eligible persons with developmental disabilities;
- (b) Assessment and periodic reassessment to determine each individual's strengths, functional limitations and need for specific services;
- (c) Development of, with the individual and his or her family, an individualized habilitation plan as specified in Section 123 of the DD Act;
- (d) Referral to and coordination of needed social, medical, educational, support and other services as identified in the individualized habilitation plan;
- (e) Monitoring to ensure the delivery of appropriate services to the individual and his or her family, and to determine individual progress in meeting goals and objectives specified in the individualized habilitation plan;
- (f) Advocacy to assist the individual in obtaining all services to which he or she is entitled and to effect changes in the service delivery system that will result in the individual's increased access to services;
- (g) An appeals process by which individuals may contest decisions pertaining to eligibility for case management services and assessment of the need for, or entitlement to, services; and
- (h) Timeliness of response consistent with the urgency of the needs of the person.

Therefore, the Illinois Planning Council on Developmental Disabilities supports the concept of independence of interagency case management systems from the traditional service delivery system.



COMMUNITY LIVING POLICY

Adopted on May 24, 1989

All persons with developmental disabilities have the fundamental right to live, work and spend leisure time in natural community settings where friendships and other relationships can occur. Integration occurs when persons with disabilities share natural, regular spaces with all citizens within local communities.

People shall have choices of how, where and with whom they want to live. Choice and decision-making should be well informed, and must include direct experience in the options from which the individual will make a choice or decision. Community residences shall be comparable in size, design, scale and decorum with others in the immediate neighborhood. A disproportionate number of persons with disabilities in a given neighborhood is strongly discouraged.

Services for people with developmental disabilities shall promote independence, productivity, and integration, and must be the highest possible quality. These services should be designed to meet the preferences, needs, wants, and desires as expressed by consumers. It shall be recognized that all behavior is communicative. Consumers who require support in communicating their preferences, needs, wants, and desires shall have a right to assistance from a guardian or significant other. To this end, ongoing consumer driven evaluations should be developed and should be conducted in such a way as to demonstrate consumer input and outcomes related to the consumers' quality of life and happiness.

Support services, including cash subsidies and family support, shall be made available to families of children, youth, and adults with developmental disabilities to prevent the demand for out-of-home placement because of the families' financial or caregiving stress. Individual and family support services shall be available to persons with developmental disabilities who live in their own homes or have their own families. Such services shall be provided with the intensity required for the person and/or family and shall be individually planned.

IPCDD shall promote and develop cooperative relationships with organizations representing generic service advocates and providers. IPCDD will support the usage, quantity and quality of generic services available to citizens with developmental disabilities. IPCDD shall encourage the development of public policy that promotes community living opportunities. Such policy shall include, but not be limited to, the elimination of zoning laws that impede or obstruct the development of integrated community residences.

It is, therefore, the policy of IPCDD to encourage, promote and support the delivery of necessary supports and services to persons with developmental disabilities from generic service providers. Typical supports and services are housing services, employment, health, mental health, transportation, leisure and recreation, education, social and legal services.

EARLY INTERVENTION POLICY

Adopted on May 24, 1989

All children have the right to be born well, to become well, and to develop to their maximum potential. The goals of early intervention should be: to prevent the occurrence of developmental disabilities; to enhance the development of children who have a developmental delay, disability or are at risk; to ameliorate the effects of their disabilities; and to support families as the most integral societal unit in promoting the child's growth and development.

Early intervention should include, but not be limited to: prevention, identification, location, screening, evaluation, diagnosis, referral, family support, and care for infants and young children with, or at risk of, developmental delays and disabilities and their families. Care should include, but not be limited to, physical therapy, speech and language therapy, health care, educational services and parent education and counseling, depending on the needs of the child and the family. Family support should be the center of all interventions.

Education, health, mental health, social services and other generic services must be coordinated to assure comprehensive services because no single agency can provide all services needed by the child and family. When day services are needed outside the home, these services would be provided in settings that serve children of the same age who are not identified as disabled.

FREE AND APPROPRIATE PUBLIC EDUCATION POLICY

Adopted on May 24, 1989

IPCDD recognizes the central role of education and Public Law 94-142 in the lives of people with developmental disabilities in achieving the outcomes of independence, productivity, and integration into the community. IPCDD believes that the principle of a free and appropriate public education is critical to ensuring access to all educational services by people with developmental disabilities and, therefore, believes that Illinois localities should be monitored closely for compliance with the free and appropriate public education requirements of the law. To ensure the underlying principles of a free and appropriate education for each and every child or youth with a disability, no group of individuals with a specific disability will be exempt. IPCDD will work to ensure that no individual child's or youth's rights will be diminished as a result of advocacy for such exemption.

The policy of IPCDD in working to implement, in Illinois, the provisions of Public Law 99-457, the Education of the Handicapped Act Amendments of 1986, is that state and local decision-makers develop a broad-based definition of the terms "educational" and "educationally-related" services in order to provide increased access to free and appropriate public education services for infants, toddlers and preschoolers with special needs and their families, without regard to income.

A free and appropriate public education for all special education students, ages three and above in Illinois, is currently a requirement for all states mandated by provisions of Public Law 94-142, the Education of All Handicapped Children Act.

PREVENTION POLICY

Adopted on May 24, 1989

Due to advances in science and technology, we now know how to prevent the occurrence of many disabilities. Thus, we can eliminate the unnecessary stresses a disability may place on individuals and families. Prevention strategies should include primary, secondary and tertiary efforts. Primary prevention represents the attempt to eliminate the causes of developmental disabilities and to reduce their prevalence. Secondary prevention should identify a problem early so that intervention at the outset will eliminate the potential for or alter the circumstances which can create a developmental disability or the exacerbation of a less severe disability. Tertiary prevention should minimize the long-term disability or at least mitigate some of its effects.

Ever increasing resources and efforts should be directed toward prevention. The Illinois Planning Council on Developmental Disabilities believes that investment in prevention is investment in tomorrow.

USE OF SEVERE PUNISHMENT OR ADVERSIVES WITH PERSONS WITH DEVELOPMENTAL DISABILITIES POLICY

Adopted on May 24, 1989

The Illinois Planning Council on Developmental Disabilities (IPCDD) advocates for the rights of people with developmental disabilities. These rights include the right to live, develop, and fully participate in society, the right to be treated with dignity and respect, and the right to live free from mental, physical, or emotional harm.

The use of severe punishment or aversives and deprivation procedures are in direct conflict with the rights of people with developmental disabilities. Aversives and deprivation procedures violate the right to be free from harm, causes loss of dignity, and prevents full participation in society.

IPCDD supports an end to any procedure which exhibits any or all of the following characteristics:

- (1) obvious signs of physical pain experienced by the individual;
- (2) potential or actual physical side effects, including tissue damage, physical illness, severe stress and/or death that would appropriately require the involvement of medical personnel;
- (3) dehumanization of the person with a disability because the procedures are normally unacceptable for non-disabled persons in community or other publicly supported environments, such as public schools;
- (4) ambivalence and discomfort by family, staff and/or caregivers regarding the necessity of such extreme strategies or their own involvement in such intervention; and
- (5) obvious repulsion and/or stress felt by non-disabled peers and community members who cannot reconcile extreme procedures with acceptable standard practice.

IPCDD supports and strongly encourages:

- (1) programs and treatments focusing on positive reinforcements, environmental adaptations, and prevention of maladaptive behaviors;
- (2) procedural safeguards including review and approval processes that assure that least restrictive procedures are used. The procedural safeguards include interdisciplinary team meetings, local human rights committees, state human rights committees, and State Protection and Advocacy Programs;
- (3) competent staff who have ongoing training in state-of-the-art programming that is positive; and
- (4) the development of alternative programs that are appropriate and positive in nature.

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